

Patient reported experiences of using community rehabilitation and/or support services whilst living with a long-term neurological condition: a qualitative systematic review and meta-aggregation.

Abstract

Objectives: To identify patient reported experiences of using community rehabilitation and/or support services whilst living with a long-term neurological condition, and perceptions of their impact on quality of life. **Methods:** Nine electronic databases were searched for peer-reviewed qualitative studies from 2005-2016, which met the inclusion criteria. Critical appraisal, data extraction and quality assessment of thirty-seven included papers were performed by 3 reviewers. One hundred and one findings were extracted. Meta-aggregation was used to synthesise findings. **Findings:** Seven ‘synthesised findings’ [SF] were produced: Interactions with some professionals provide active participation, choice, confidence and autonomy [SF1]; Interactions with some professionals are disempowering and depersonalized [SF2]; Effective communication, specialist knowledge and an individualized approach to information provision is needed [SF3]; Indicators of success vary and may not be clear [SF4]; Informal support from family/friends is valued [SF5]; Opportunities for peer support/social interaction is valued [SF6]; Coordination required to ensure continuity during transition to community [SF7]. **Conclusion:** Patient reported experiences identified common factors associated with process quality (respect, choice, autonomy, information provision, communication) and activities of patient centred care (personalised care, shared decision-making, self-management support) despite heterogeneity of neurological conditions, service configurations and geographical location. These factors impact quality of life.

Keywords: Community based, Patient Centred, Process quality, Self-efficacy, Self-management, Service Redesign.

INTRODUCTION

The prevalence of people living with long-term neurological conditions (LTNC) is increasing globally in the context of an ageing population [1,2] and claims on current resources are reported to be unsustainable [3-5]. Despite policy and guidelines about community service provision [6-9], recent evidence indicates that community services are not adequately supporting quality of life for people with LTNC or preventing crises and/or acute admissions [3,10-14]. It has been proposed that innovative redesign of community services for people with LTNC is required to improve quality, efficiency and patient outcomes [3,5,15,16].

Models of community rehabilitation and support services

Numerous models of community rehabilitation and support services exist from outside and/or inside the primary health sector and from public, private or independent health and social care organisations [3,11,18-21]. The underpinning philosophy affects the aims and scope of the service which can range from a medical focus on neurological impairments and dysfunction, to a social model which addresses barriers to participation in society [3,22-26]. A human rights approach to rehabilitation is also described where Community Based Rehabilitation (CBR) is ‘a community development strategy for rehabilitation, equalization of opportunities and social inclusion of all people with disabilities’ [27,p.26]. Whilst the concept of CBR originated in low and middle-income countries in the 1960’s [22,27,28], it has more recently been applied to community rehabilitation in higher income countries [23-25] and to services for people with LTNC [3,26,29]. Community support for people with long term conditions is also part of health and social care models such as the Value Based Practice Model [30] Chronic Care Model [31, 32], and more recent, House of Care model [33]. Availability of rehabilitation and support for people with LTNC varies considerably across geographical location [24], as does the mode of delivery, which may be from specialist community neurological rehabilitation teams, generic community teams or individual health and social care professionals [6,7,20,21]. Clarity about the scope of community rehabilitation and support services for people with LTNC in the UK is

offered by Quality Requirement 5 of the National Service Framework for LTNC, which defines services delivered at home, in the community or in outpatient settings [7,p.35-37].

Patient centred care and quality of services

The Institute of Medicine defines patient centred care as “respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” [17,p.6]. Principles of patient centred care (respect, coordination/integration, information/education, physical comfort, emotional support, involvement of family/friends, continuity/transition and accessibility) [34-36] and activities associated with patient centred care (personalised care, self-management support and shared decision making) have also been described [37-40]. These principles have been used to consider quality of service delivery and to compare health strategies within and between different countries [4,17,34,39-42]. ‘Process quality’ refers to ‘the way that people are treated’ and a need for indicators to measure process quality of community rehabilitation and support has been identified [40,43-46]. The dimensions of ‘process quality’, courtesy, respect, choice, autonomy, information provision and communication [43], clearly concur with principles of patient centred care [34-36]. Numerous authors emphasise that monitoring of process quality requires data about experiences of using services [17, 47-50] and that this is more useful than data about patient satisfaction [17,50]. The importance of a good patient experience has been recognised [15,46,48,51] and Patient Reported Experience Measures are being introduced [15,47,49,52]. Entwistle et al [47] used a critical interpretive approach to explore which health care experiences are important to people and two categories emerged: 1) “experiences of what health services and staff are like and do” and 2) experiences of how individuals are enabled “to be and do what they value being and doing” within and beyond health care encounters. The latter suggests that the degree to which service users’ commit to and actively participate in the rehabilitation process (engage) is important [40,53-55] and a positive influence on outcomes associated with quality of life has been noted [50,56,57]. Furthermore, evidence has identified that strategies which promote

engagement during the neurological rehabilitation process have the potential to yield neuroplastic changes and improved functional outcomes for people with LTNC [25,58,59].

Research into patient experiences

Research into patient experiences of neurological services has increased in recent years. Questionnaire surveys have given some indication of progress in satisfaction with neurological services but also highlight concerns about delayed diagnosis [12,52], referral and access to neurological specialists [13,60-62], cognitive and emotional support [61-64], a fragmented pathway, and clarity about the processes for monitoring local community rehabilitation and support services [12,13,52]. Discrepancies have been identified between peoples' experiences and service commissioners' perceptions of how community services are being delivered [12,45,65].

While questionnaire surveys are commonly used, they have limitations in that they often fail to capture rich qualitative data, due to variations in questions and response options, data weighting and lack of opportunity for expression [66,67]. The difficulty in finding the appropriate language to adequately report on community rehabilitation and support has also been noted [52]. It is argued that qualitative research is a more appropriate approach as it is ethically consistent with a patient centred philosophy and it can inform evidence-based services [66,68,71]. Furthermore, it can play a major role in capturing people's experiences and perceptions of the process of health services using "data collection strategies that 'touch the core' of what is going on rather than just skimming the surface" [70,p.16]. Current qualitative research provides examples of how experiences of people with a diverse range of LTNC can produce rich data about the process of delivering patient centred, integrated health and social care services [46,65,72]. For example, Sixsmith et al. [65] used the quality requirements of the UK National Service Framework for Long Term Conditions as a basis for exploring views of people with different LTNC (Multiple Sclerosis (MS), Brain Injury, Stroke, Spina Bifida,

Parkinsons' Disease (PD), Epilepsy, Cerebral Palsy, Cerebellar Syndrome, Lesch Nyhan). This highlighted concerns about delay in diagnosis, access to specialist care and/or need for integration [connectivity] between health and social services [65]. Also, Aspinall et al. [46] explored patients perspectives of models of integration within health and social care with the aim of improving experience of integration and continuity of care for people with different LTNC (MS n=6, Stroke n=3, other n=3) in England [46]. More recently Tod et al [72] explored 'good quality' social care using experiences of people with PD (n=43), carers, and professionals in community settings.

Qualitative research relating specifically to experiences of community rehabilitation and support services includes numerous studies focussing on Stroke [71,73,74]. There are less but some qualitative studies into experiences of using community rehabilitation and support services for people with other LTNC [75-78]. The available research uses various approaches to define services and/or the process of receiving support. Van de Eijk et al [75] explored the experience of people with PD (n=40) and their carers (n=20) living at home and receiving services in the Netherlands, using the Picker Institute principles of patient centred care [35] and the WHO responsiveness model [79] as frameworks for analysis. Unmet needs and patient preferences were revealed, enabling a disease specific theoretical model of individualised patient centred care for PD and a 'patient-centredness' questionnaire to be developed. Methley et al [76] explored patient (n = 24) and professional (n =34) perspectives of UK primary care provision for people with MS, highlighting how 'patient centredness' is valued, and how relational continuity of care improves responsiveness of services to individual needs. An alternative approach within the research literature has been to focus on a specific activity of patient centred care such as self-management for people with MS (n=18) [77] or information provision during diagnosis of MS [78]. Findings from both these studies suggest a positive relationship between collaborative interactions with professionals, adjustment to living with a LTNC and effective self-management. Other studies have focussed on experiences of vocational rehabilitation, which is one element of community rehabilitation and support [80-83]. Perspectives of people

with MS [80,81] and Acquired Brain Injury (ABI) [82,83] revealed the following specific vocational rehabilitation needs: support and advocacy during liaison with employer [80,81]; expert information about the employment setting and alternatives [80-82] and understanding of the grief experienced during re engagement in occupation [83]. Current research evidence indicates that people with different neurological conditions share similar views about the community rehabilitation and support services they use.

In addition to primary qualitative studies, a number of researchers have used qualitative systematic reviews to facilitate synthesis of the experience of using health services [74,84,85]. For example, Lawrence et al [74] synthesised stroke survivors and family members perspectives of secondary prevention interventions and Methley et al [85] reviewed experiences of people with MS utilising UK health services. However, there have been no previous qualitative systematic reviews of patient reported experiences, focussing on the utilisation of community rehabilitation and support services, for people with a range of LTNC. It is therefore proposed that qualitative findings about experiences of these services could enhance the existing evidence base and provide an insight into process quality of community rehabilitation and support for people with LTNC. The purpose of this systematic review was to identify and synthesise the best international qualitative evidence to answer the following question: How do people with LTNC experience community rehabilitation and support services?

Review Objectives:

- To identify patient reported experiences of using community rehabilitation and/or support services whilst living with a long-term neurological condition.
- To identify service users' perceptions of the impact of community rehabilitation and/or support services on their quality of life.

METHODS

A qualitative systematic review was undertaken using the Joanna Briggs Institute (JBI) approach, which offers an internationally recognised, rigorous pathway and tools for each aspect of the systematic reviewing of qualitative research evidence [70,86,87]. The review is one element of a larger programme of work (which includes quantitative and mixed methods studies). The systematic review question and inclusion criteria were framed by using the PICo mnemonic (**P**opulation, phenomenon of **I**nterest; **C**ontext) established by the JBI [70].

Population included individuals with progressive (MS, PD) and stable (ABI other than stroke, Dystonia) LTNC to represent diversity [4]. The International Classification of Functioning Disability and Health (ICF) was used to communicate and conceptualise the focus on patient reported experiences relating to activity and participation domains [88-91]. The scope and range of community rehabilitation and support services was defined by Quality Requirement 5 of the UK National Service Framework for LTNC [7,p.35-37].

(P) Population: Adults, age > 18, living with progressive (MS, PD) and stable (ABI other than Stroke, Dystonia) LTNC [4] who are using Community Rehabilitation and Support services.

(I) Phenomenon of Interest: Patient reported experiences of community rehabilitation and support services which relate to the activity and participations domain of the ICF [88]

(Co) Context: Community rehabilitation and support services which enable and support people with LTNC to lead a full life, provided at home, in the community or in an outpatient setting [7,p.35-37].

Types of Studies: All qualitative designs, to capture the whole phenomenon of interest [70] including but not restricted to, phenomenology, grounded theory, ethnography, action research, descriptive qualitative studies and case studies.

Search strategy: A comprehensive, sensitive search strategy was developed in MEDLINE.

The initial search in MEDLINE used key words (relating to progressive and stable LTNC (PD, MS, ABI, Dystonia), patient reported experiences, and community rehabilitation and support services, to identify indexing terms, medical subject headings and further free text terms [Supplementary table S1]. The list of search terms developed from this was then used with Boolean operators to search the following online, bibliographic subject based data bases: CINAHL, PsychInfo, AMED, ASSIA, BNI, EMBASE, PEDRO and OT SEEKER. An internet search of websites including the MS Society, Headway and the Dystonia Society was also carried out. Finally, hand searching of key journals took place and reference lists were checked for additional studies. Papers from 2005–2016 were included. This enabled collation of information about community rehabilitation and support services since the introduction of the National Service Framework for LTNC [7]. Limits of abstract and English language were applied. Bibliographic management software, RefWorks, was used to store and organise references.

Study selection: Following de-duplication a four-stage process was used to identify studies according to predetermined inclusion/ exclusion criteria [Supplementary table S2]. Stage 1: Initial selection and screening of title by lead reviewer. Stage 2: Initial screening of title and abstract and exclusion of those that did not meet inclusion criteria independently by lead reviewer and a second reviewer. Stage 3: Retrieval of full text, screening and selection of papers independently by lead reviewer and the second reviewer. Stage 4: Assessment of methodological quality independently by lead reviewer and second reviewer.

Methodological quality assessment: Each paper which met the inclusion criteria was assessed independently by two reviewers for methodological quality using the critical appraisal questions from JBI Quality Appraisal Review Instrument (QARI) as seen in box 1 [70]. Studies were deemed to be of sufficient quality if they scored ‘Yes’ for at least 4 questions and the

answer to question 8 was ‘Yes’. Any disagreements were resolved by discussion, and where necessary by a third reviewer. We then went on to assess JBI ConQual score where the decision for each question and the total score for ‘Yes’ answers to questions 2,3,4,6,7 was recorded for each paper [86 Supplementary table S3]. These scores were later used after meta-aggregation to assess dependability of ‘synthesised findings’ [87].

INSERT box 1 here

Data extraction: The standardised JBI data extraction tool [70] was piloted on five of the articles to ensure that constructs were being interpreted consistently, and discussion took place between the research team to clarify any areas of concern [92]. The lead reviewer then extracted all specific details about the phenomena of interest, population, context/setting, study methods, and pooled findings of relevance to the review question (and text/quotes/illustrations to support each finding) [86]. The review team then followed the JBI method of grading each included finding using a ranking scale of ‘unequivocal’ ‘credible’ or ‘unsupported’ [86].

Data Synthesis: A process of meta-aggregation was used to synthesise the qualitative findings [70,86,87]. First, the unequivocal and credible findings from included studies were repeatedly read by the lead researcher and categories were created based on similarity of meaning. Following this, categories were grouped into similar themes, and a preliminary series of statements, known as ‘synthesised findings’, were devised (two or more categories to each statement) [70, 86].

Two other members of the research team then read and reread the findings, categories and ‘synthesised findings’ to reduce interpretation bias. Discussion took place to achieve consensus of final categories and ‘synthesised findings’. Finally, the JBI ConQual tool was used to establish confidence (defined as the belief or trust that can be placed in the results of the research) through an assessment of credibility and dependability for each synthesised finding [87 see Supplementary table S4].

FINDINGS

Findings are reported according to the guidelines outlined in the Preferred Reporting Items for Systematic reviews and Meta-Analyses statement - PRISMA [92] (includes quantitative and mixed methods papers not reported here).

Results from systematic search: 12,941 references (disregarding duplicates) were identified and then reduced to 685 after review of title/title and abstract [see figure 1]. One hundred and forty-one qualitative papers were retrieved for review of full text, of which 53 papers met the inclusion criteria [14,65,72,75,78,80,82,83,90,94-137]. All 53 papers were then assessed for methodological quality independently by two reviewers and 37 adequately met JBI quality criteria [14,65,75,80,82,83,90,95-108,111,113,114,116,117,121-124,128,131-135,137]. Sixteen were excluded as they either did not adequately represent participants and their voices in relation to their experiences of using services, and/or did not adequately address the influence of the researcher on the research or address ethical considerations [72,78,94,109,110,112,115,118-120,125-127,129,130,136].

INSERT Figure 1 here

Description of studies: The 37 included papers used a range of qualitative designs and data collection methods enabling exploration of the phenomena of interest from a variety of angles, (see table 1). Thirty-five used condition specific sampling and two used samples of a range of people with LTNC. Included studies were of acceptable methodological quality with a 'Yes' answer to JBI QARI question number 8 and at least 4 yes answers in total. The main area of methodological weakness for the few studies with lower scores was related to inadequate reporting about the researchers' culture and influence [Question 6 and 7 of JBI QARI see box 1, Supplementary table S3].

INSERT Table 1 here

Characteristics of participants: Seventeen studies reported experiences of people with ABI (n=205), thirteen reported experiences of people with MS (n=136) and nine reported experiences of people with PD (n=119). No studies explored experiences of adults with dystonia. The age range was between 17 – 82 years, representing experiences of people with neurological conditions across the lifespan. All participants were adults over the age of 18 except for one individual who was aged 17 and was included in one sample (n=20) [132, 133]. Six papers did not state the exact ages of participants [95,96,103,104,111,113] but stated that they were adults. Turner et al. [132,133] included four people with aneurysm stroke in their sample of 20 people with ABI and it was not possible to separate their data. It was decided to include the data in the qualitative synthesis due to its high quality and relevance. Male (n=253) and female (n=235) participants were represented within the studies. However, the exact number is unknown since four of the studies did not report gender [96,99,103,104].

Characteristics of Phenomena of Interest and Context: Experiences of community rehabilitation and support services provided in the home and local environment and experiences of day centre and outpatient programmes were reported. These targeted five activity and participation domains of the ICF (communication, mobility, self-care, domestic life, interpersonal interactions/relationships) across a range of geographical locations [88 see box 2]. Insufficient detail was provided to ascertain whether services were within metropolitan or rural settings.

INSERT Box 2 here

Meta aggregation process and ‘synthesised findings’: One hundred and one qualitative findings of relevance to the study objectives were extracted from the studies, with the majority of these being graded as ‘unequivocal’ and a few as ‘credible’ [86]. These were grouped into 17 categories, which merged to create seven ‘synthesised findings’: *Interactions with some professionals provide active participation, choice, confidence and autonomy; Interactions with some professionals are disempowering and depersonalized; Effective communication, specialist*

knowledge and an individualized approach to information provision is needed; Indicators of success vary and may not be clear; Informal support from family/friends is valued; Opportunities for peer support/social interaction is valued; Coordination is required to ensure continuity during transition to community. Table 2 presents detailed descriptions of the ‘synthesised findings’ and the categories from which they were developed.

INSERT table 2

Due to the need for brevity it is not possible to present all the qualitative data from studies. However, examples of the meta-aggregation process for three of the ‘synthesised findings’ is provided to aid understanding of the process and insight in to the rich data (see tables 3 and 4). Further illustrative examples can be found in supplementary tables (S5-S10). Overall credibility of all seven ‘synthesised findings’ was rated as high by the ConQual assessment process, as the majority of findings from individual studies were ‘unequivocal’. Downgrading by one level of dependability for SF6 and SF7 took place during assessment with the ConQual tool, due to inadequate reporting about researchers’ influence in some studies (see Supplementary tables S3 and S4).

INSERT Table 3

INSERT Table 4

INSERT Table 5

DISCUSSION

This paper presents a synthesis of qualitative evidence from 2005-2016, on ‘patient reported experiences of using community rehabilitation and/or support services whilst living with a long-term neurological condition’. Meta-aggregation produced seven ‘synthesised findings’ (SF1-7 see table 2) which contribute to a fuller conceptual understanding of patients’ experiences of using these services (Objective 1) and the impact that interactions within community rehabilitation and support services have on outcomes related to QOL (Objective 2). The

discussion below is focussed around the seven ‘synthesised findings’ which are inter related and overlapping.

Although the evidence supporting patient centred care [17,34-37] and shared decision making [38-40] is extensive, our systematic review adds depth to our understanding of how interactions within community rehabilitation and support services can influence the experience of these concepts. ‘Synthesised finding’ 1 (*SF1: Interactions with some professionals provide active participation, choice, confidence and autonomy in decision-making*) clearly demonstrates that engagement (active participation) during encounters with professionals is valued. However, ‘synthesised finding’ 2 (*SF2: Interactions with some professionals are disempowering and depersonalized*) identifies that more traditional didactic approaches continue to exist, which do not accommodate preferences and individual needs of people with LTNC. Whilst the literature on information provision is considerable [39,78,138,139], ‘synthesised finding’ 3 (*SF3: effective communication skills, specialist knowledge and an individualized approach to information provision*) revealed that it is essential for it to be accurate, timely and for the knowledge acquisition process to be supported, if it is to empower people with LTNC. However, we found that the process of providing information is not always adequate within community rehabilitation/support services for people with LTNC. This reinforces previous research highlighting the need for advanced communication skills (e.g. respect, empathy, listening and coaching) on the part of health professionals, to appreciate intrinsic and extrinsic factors for each individual during the rehabilitation process [42,53,55,74,140-142]. What is clear from this current review is that data about experiences provides important information about dimensions of process quality (courtesy, respect, choice, autonomy, information provision, communication). Our ‘synthesised findings’ demonstrate that process quality is determined by interactions, and that it is a prerequisite for activities of patient centred care, such as personalised care and shared decision making.

Our ‘synthesised findings’ also provide new knowledge about how community rehabilitation professionals can influence engagement (active participation) and motivation through their interactions. This is congruent with a contemporary definition of engagement such as that offered by Bright [53], where it is not only a state (within the individual) but also a process (‘engaging in’) in which clinicians play an important role. These findings are really important for people with neurological conditions as the scientific evidence has also shown the link between engagement, an increase in neural plasticity and improved motor control [58, 59]. Synthesised finding four and five propose two strategies to enhance engagement within community rehabilitation and support services, from the perspective of those using the services. Firstly, ‘synthesised finding’ 4 (*SF4: Indicators of success vary and may not be clear*) demonstrates that people with both stable (ABI) and progressive (MS) LTNC believe that goals have the *potential to provide structure, motivation and satisfaction*, supporting current research for patient centred goal planning [143-146]. Secondly, ‘synthesised finding’ 5 (*SF5: Opportunities for peer support/social interaction is valued*) adds to the growing evidence for peer support groups [147,148] by highlighting how this impacts motivation, self-efficacy and self-management. On the strength of this, the authors recommend routine usage of both these strategies within community rehabilitation and support services for people with LTNC.

The meta-aggregation of patient experiences has produced strong evidence that self-efficacy (feeling in control), independence and self-management are important for people with LTNC. The review embraces the notion that the experience of process within services impacts self-management. This prompts a critical exploration of ‘self-management’, which has been described as an activity associated with patient centred care [37-40] and as an outcome of community rehabilitation and support services [77,149]. Self-management ranges from a narrow concept influenced by biomedicine and psychology, to a broader concept influenced by a social model of health or human rights, [5,40,149-151]. This review supports a relational approach to self-management, which recognises the importance of interactions which promote self-efficacy [76,77,151-156], rather than an instrumental approach which purely uses self-management

tools/activities in response to external drivers and/or resource constraints [38,39,45]. The authors challenge community rehabilitation and support services for people with LTNC, which focus purely on the latter approach, and the concept of ‘self-management programmes’ which run in addition to traditional services. We argue that limitations with an instrumental approach to service delivery exist, in that the influence of interactions, and/or the potential role that all community rehabilitation services can play to promote self-efficacy and self-management for people with LTNC is not fully appreciated. The authors believe that this complex relationship between interactions, engagement, self-efficacy and self-management for people with LTNC has not been adequately dealt with in current research.

However, the majority of people with LTNC are self-managing most of the time and interactions with professionals are one small aspect of their lives [31,40,56,149,150].

‘Synthesised finding’ 6 (*SF6: Informal support physical, emotional, administrative) from family and friends is valued*) reminds us of this and identifies that people with LTNC perceive that *informal support could be maximised with appropriate assistance from community rehabilitation and support services*. These ideas support the argument that individual environments and social situations should frame rehabilitation and support, which is a core principle of Community Based Rehabilitation [25,27,28], and it also underpins recent health and social care models for chronic conditions [30-33]. Other important principles for community provision are accessibility and responsiveness [27,30-33,43], and there is a large body of research emphasising how flexible, open access to community services is crucial due to the fluctuating nature of neurological conditions and associated needs [12,65,72]. However, ‘synthesised finding’ 7 (*SF7: Coordination required to ensure continuity during transition to community*) demonstrated that some people with MS and ABI continue to experience *lack of continuity and/or access*. We discovered that some people with ABI believe that *case-management* could help improve continuity during transition to the community. This reflects findings elsewhere, which suggest that case management can improve communication and co-production of health for people with LTNC [21,32,54]. In addition, a previous qualitative study

recently identified that relational continuity of care enhances responsiveness for people with MS [76]. We believe this current systematic review clearly highlights the benefits of relational approaches, which are considerable, and are transferable to people with ABI, PD and potentially all LTNC.

The authors agree with previous literature suggesting that innovative redesign of community rehabilitation and support services should be informed by service users [12,49,63,64,156-159] and propose that this is facilitated by this systematic review. The ‘synthesised findings’ have provided new knowledge about the interconnectivity between process quality, engagement, self-efficacy and self-management. We have demonstrated that an individualised approach which promotes self-efficacy (feeling in control) and engagement (active participation) has the potential to improve the quality of life for people with stable and progressive LTNC, using community rehabilitation and support services in a range of countries. This has important consequences for how we interpret and measure quality and effectiveness of process within services. Our work produced practical suggestions from people with LTNC, which support current research. On a philosophical level, it has become clear from the discussion above, that models of health and rehabilitation that prioritise human rights and value of individuals, are conducive to a good experience, and will therefore be fundamental during redesign of community rehabilitation/support services for people with LTNC.

Strengths and limitations:

JBIM methodology for systematic reviews is internationally recognised for its rigour and quality. In this paper it has supported synthesis of qualitative data into generalisable statements and/or recommendations [70,86] which can inform redesign, delivery and evaluation of future patient centred community rehabilitation and support services. Three reviewers were involved in the systematic review process in order to minimise researcher bias. The search strategy enabled meta-aggregation of patient reported experiences from people with stable and progressive

LTNC across a number of countries, despite heterogeneity of service configurations. It is recognised that legal and financial context for services was not considered and outside the remit of this study. Whilst a robust search strategy was used, and every effort was made to identify pertinent studies published in English, we note that patient reported experiences of community rehab and support services, which were published in other languages are not represented. It is also possible that some studies may have been missed. This is primarily because qualitative studies can be difficult to identify [70], the level of archiving can often be poorer than for quantitative studies [160] and qualitative data on patient experiences may not be published in peer-reviewed journals. A final limitation was the downgrading for dependability of 'synthesised finding' 6 and 7. However, both were downgraded only one level and largely due to studies failing to report on the culture or influence of the researcher (Q6 and Q7 see box 1), rather than fundamental methodological flaws (Q2,3,4 see box 1).

Clinical/service implications:

This systematic review raises implications, which have broad international applicability for community rehabilitation and support services for people with LTNC. First, it has extended our understanding of how the process of receiving community rehabilitation and support can be captured by patient experience data. Current and future community rehabilitation and support services should therefore consider how patient reported experiences could be used as indicators of process quality during monitoring and evaluation of activities of patient centred care.

Second, we have identified that quality improvement interventions at the level of the individual professional are required through the optimisation of interactions and behavioural change. It is proposed that advanced communication skills and specialist knowledge about LTNC should be an integral part of workforce training in order to ensure that existing community rehabilitation and support services for people with LTNC can improve process quality and outcomes associated with process (self-efficacy and self-management).

Third, we have highlighted that successful redesign of services will require leadership that can create a receptive context for behavioural change at all levels of the organisation [161]. Open discussion will be required using clear language and working definitions to develop a workforce with a shared understanding of models of health and rehabilitation, person centred care, process quality, self-efficacy, engagement and self-management. Existing networks and forums committed to quality improvement within community rehabilitation and support [12,45,162] should be supported and further opportunities for networking between health, social care and the independent sector should be encouraged.

Implications for research:

It is proposed that a broad search strategy is useful for future research into community rehabilitation and support services for people with a range of LTNC and a range of service configurations. Further empirical research is needed in a number of areas. Firstly, to explore how experiences of rehabilitation and support can be enhanced for people with LTNC during key stages in their lives (e.g. early transition to community). Secondly, patient reported experiences of self-management programmes could be collated to determine whether they achieve outcomes of self-efficacy and self-management. Finally, further qualitative enquiry exploring the process of engagement (active participation) during interactions within community rehabilitation and support services would be useful to specify the attributes, skills and competencies required to promote self-efficacy and self-management. Dissemination of research findings with managers and leaders of health and social care services is necessary.

CONCLUSION

This qualitative systematic review identified similarity in experiences for people with stable (ABI) and progressive LTNC (MS, PD), across a number of different countries, despite heterogeneity of service configurations. It produced new knowledge about how patient reported experiences provide information about process quality (courtesy, respect, choice, autonomy,

information provision and communication) and activities associated with patient centred care (personalised care, self-management support, shared decision making), and that these are seen as important by people with LTNC. We learnt that people with LTNC perceive that interactions with individual professionals do have an impact on engagement (active participation), self-efficacy and self-management. The review was conducted to rigorous international standards and has highlighted new knowledge to inform future policy and service provision for community-living people with LTNC.

Declaration of Interest The authors report no conflict of interest. The authors alone are responsible for the content and writing of this paper.

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Table 1: Descriptive detail of 37 qualitative papers included in the review.

AUTHOR, STUDY DESIGN, CONTEXT AND LOCATION.	PHENOMENA OF INTEREST	PARTICIPANTS, SAMPLING AND RECRUITMENT	DATA COLLECTION METHODS	DATA ANALYSIS
Archer et al 2014 [95] Qualitative South Australia & Northern Territory Australia	Experiences of driving assessment and rehabilitation.	9 participants with MS and 6 professionals Age not stated. Gender: M=2 F=7 Recruited via MS society, 5 currently driving and 5 not driving.	Focus groups: Two with people with MS and one with professionals. Venue not stated.	Thematic analysis
Armitage et al 2009 [96] Descriptive, qualitative. Bristol, Cambridge, Liverpool, Sussex, UK	Experiences of provision in care homes for people with PD.	24 participants with PD. Age not stated. Gender not stated. Recruited via 43 care homes in 4 Local Authorities. Resident in residential care setting for at least 2 months, British, English as first language, able to give informed consent.	24 in -depth individual interviews, (and analysis of care plans). Conducted in residential care home with relatives (when requested).	Thematic analysis
Boss and Finlayson 2006 [97] Grounded theory Illinois, US	Personal experience/responses to acquisition and use of power mobility devices.	7 participants with MS , and 4 family members. Age: 31–65. Gender: M=2 F=5 Recruited via MS society. English speaking, acquired/ acquiring power mobility, living with one + family member, using/desiring to use power mobility inside or outside.	Face to face, individual, semi - structured interviews in participants' home.	Constant comparative method (using ATLAS software)
Chamberlain 2006 [98] Qualitative Adelaide, Australia	Experiences of people with one year post TBI.	60 participants with TBI Age: 18 -81 (Median 35) Gender: M=40 F=20 Recruited 1 year post admission to Intensive Care Unit following mild, moderate, severe, critical TBI (Traumatic Brain Injury Severity Score). Regular contact post ICU.	Unstructured in-depth interviews. Majority at home with family member present (care to avoid their input)	Qualitative content analysis
Clarke and Coote 2015 [99] Qualitative Limerick, Ireland	Experiences of participation in RCT: community and MS group exercise.	14 participants with MS Age: (Mean 53.9) Gender: not stated Participants in RCT for group exercise led by Physiotherapist (Group A n= 5 and C n= 3) or Fitness Instructor (Group B n= 6), mean time since diagnosis 10.3 years.	Three focus group interviews at venue of exercise programme.	Thematic analysis
das Nair et al 2013 [100] Qualitative, critical realist Nottingham, UK	Experiences of participation in RCT: 2 types of memory rehabilitation with self-help control.	31 participants with TBI (n=4), MS (n=21), Stroke (n=6) Age: 18 – 61 (Mean 45). Gender: M=7 F=24 Recruited following participation in RCT for memory rehabilitation: “restitution” (n =9), ‘compensation’ (n =10), self-help (control) group (n =12). Diagnosed > 1 mth.	Semi-structured interviews. Venue not stated.	Thematic analysis
Dodd et al 2006 [101] Qualitative Victoria, Australia	Perceptions of positive /negative effects of a progressive resistance programme.	9 participants with MS Age: 27 – 61 (Mean 45.6). Gender: M=2 F=7 Recruited following completion of 10 week resistance programme, mild to moderate disability, did not require assistive device for walking and able to walk 200 metres.	Individual in-depth interviews at chosen venue: home (5), gymnasium (4). 3 researchers, unknown to participants. 2 of them assisted with programme design.	Thematic analysis coded manually and with QSR NUD*IST4

Doig et al 2009 [102] Qualitative, phenomenology Brisbane and Queensland, Australia	Perspectives of client-centred goal directed therapy in community (Day hospital and home).	12 participants with TBI and significant others (parents n= 12) and 3 OTs. Age: 18 -43 (mean 24.7). Gender: M=10 F=2 Recently discharged, living in community, referred for Outpatient OT, English speaking, significant other willing to participate. Average disability rating scale score 5.6.	Semi -structured interviews in participants home.	Thematic analysis
Embrey 2009a [103] Qualitative, phenomenology Stoke upon Trent, UK	Experiences of therapeutic interventions at palliative day care centre.	9 participants with MS Age not stated. Gender not stated. Moderate, severe, advanced MS and well enough to participate. Attending palliative day care service for palliative care and rehabilitation.	Open ended individual interviews at palliative day care service.	Thematic analysis
Embrey 2009b [104] Qualitative, phenomenology Stoke upon Trent, UK	Experiences of group support at a palliative day care centre.	As above Same participants as above [94] but different findings reported.	As above	As above
Fitzpatrick et al 2010 [105] Qualitative, phenomenology Lancashire, UK	Experiences of 8 week mindfulness based cognitive therapy.	12 participants with PD. Age: 57-72. Gender: M= 7 F=5 2 to 16 years post diagnosis, living at home, self-referred to mindfulness based cognitive therapy course.	Semi-structured, non-directed individual interviews before (n=10) and after the course (n=2). Venue not stated.	Thematic analysis
Fogg-Rogers et al 2016 [106] Qualitative Auckland, New Zealand.	Experiences of Choral Singing Therapy.	14 participants with PD n =6 and Stroke n= 8 Age: 53 – 7 Gender: M=8 F= 6 Recruited from community choir for people with PD, Stroke, Dementia and carers	Semi-structured interviews Venue not stated	Inductive analysis and content analysis (NVivo)
Foster et al 2015 [14] Qualitative Queensland, Australia	Perspectives of people with LTNC/significant others /care service providers on adequacy of health and rehabilitation services/ unmet needs.	25 participants with LTNC: ABI n=6, MS n = 8 , Huntingdon's Disease (n=3), Neurone Disease (n=3), Spinal Cord Injury (n=5). 22 family members/friend/informal carer, 18 service providers. Age: 20-59 Gender: M=4+3 F=2+5 All had 24-hour attendance/on call emergency care, required assistance with activities of daily, living in own home/residential care.	Individual interviews (8 with carer present) at either home or workplace	Thematic analysis
Giles and Miyasaki 2009 [107] Interpretive phenomenology Toronto, Canada	Experiences of health-care system for persons living at home with palliative stage of PD.	3 participants with PD and carers of people with PD (n=4); Age 71, 74 and 77. Gender: M= 1 F=2 Diagnosed with palliative stage PD (Hoehn and Yahr stage 2.5–5), had received neurological care at tertiary academic teaching hospital centre.	Semi-structured individual in depth interviews at either home or hospital. Patients and carers interviewed separately.	Thematic analysis
Gilworth et al 2008 [108] Qualitative, phenomenology Leeds, UK	Experiences of support for returning to work for people with BI.	33 participants with BI Age: 18 -55 (Mean 37). Gender: M=22 F=11 Mild to moderate BI (Glasgow coma scale) In work at the time of sustaining injury, blue and white -collar workers back at work/ not back at work.	Individual semi-structured interviews at patients home, university or place of work. 4 experienced researchers unknown to participants.	Thematic analysis

Hoosen et al 2013 [83] Qualitative, phenomenology North Wales, UK	Experiences of return to work rehabilitation.	10 participants with Brain Injury Age: 23 -62 years. Gender: M=8 F=2 Medium – severe, (Mayo TBI severity classification). Registered with North Wales brain injury service, awareness and insight demonstrated, in paid employment prior to sustaining injury, engaged in Return to Work Rehabilitation following TBI.	Semi-structured interviews Venue not stated	Interpretative Phenomenological Analysis
Jellie et al 2014 [80] Qualitative London, UK	Experiences of Vocational Rehabilitation Intervention.	19 participants with MS Age: 24-63 Gender: M=4 F=15 Experiencing work instability had Vocational Rehabilitation intervention.	Semi-structured in-depth interviews in home (7) or hospital setting (12).	Coding with Constant Comparison (MaxQDA)
Keighley et al 2011 [111] Participatory research Northwest Ontario, Canada	Barriers/enablers for people with ABI during transition from health care to community.	3 participants with ABI (n=3) , caregivers (1 wife and 2 parents, hospital workers (n=6,) and community healthcare workers (n=5). Age: not stated. Gender: M=2 F=1 Purposeful recruitment to represent a range of profiles.	Two focus groups with people with ABI, caregivers and community healthcare workers during health conference.	Thematic analysis
Kuipers et al 2009 [90] Qualitative, interpretive Queensland and Brisbane, Australia	Experiences and needs of people with ABI for outpatient services.	Phase 1: Professionals (Medical director, Physiotherapist (x1), Speech pathologists (X2), Occupational Therapist (x2) Phase 2: People with a diagnosis of ABI (n=18) due to trauma (9) , stroke (3) or other neurological injury (6) and able to participate in an interview. Significant others (7 mothers, 3 sisters, 1 wife, 1 father, 1 daughter, 1 grandmother, 1 brother-in-law) Age: 20-59. Gender: M=12 F=6.	Phase 1: Workshop discussions. Phase 2: Semi-structured Interviews with outpatients & significant others (separately) conducted twice (8 weeks apart), in OP dept, home or telephone.	Thematic analysis
Lawson et al 2008 [113] Auto-ethnography using narrative theory Montreal, Canada	Experiences of post traumatic brain injury community rehabilitation.	1 participant with TBI Age: not clearly stated @ 40 years old. Gender: F Moderate brain injury, previously nurse and nursing educator, 4 years post TBI	Illness narratives collated via manuscript, journal entries, poetry, individual unstructured interviews	Inductive thematic analysis
Lefebvre, H 2005 [114] Qualitative, Constructivist action research Greater Montreal, Canada	Experiences of people with TBI (families, physicians, professionals) from acute care reintegration to daily life.	8 participants with TBI (6 single, 2 married), members of their families (n=14), health professionals from varied disciplines (n=22) and physicians (n=9). Age: > 18<49 (Mean 28.4) Gender: M= 6 F=2 Moderate-to-severe TBI (without diagnosed medullar lesions), Mean years post trauma =2.8, French speaking.	Semi -structured individual interviews at home with people with TBI and family members (together), and with health professionals/ physicians in their office.	Units of meaning and themes Identified (QSR NUDIST software)
Malcomson et al. 2008 [116] Qualitative, interpretive Ulster, Northern Ireland	Experiences of living with' MS and self - management strategies.	13 participants with MS Age: 40-57 (Mean 54). Gender: M=4 F=9 Diagnosed with MS >5 years ago (mean 17 years ago). Recruited via MS Society, able to cope with the disease in daily life, willing to discuss their experiences.	Two focus group interviews Venue not stated.	Thematic analysis
Mansson Lexell et al. 2013 [117] Qualitative Lund, Sweden	Experiences of people with TBI of group rehab programme.	11 participants with TBI (n=5), Sub Arachnoid Haemorrhage (n=3) anoxic injury (n=1), brain tumour (n=1), stroke (n=1). Age 25 – 62. Gender: M=6 F=5 Recruited following participation in group rehabilitation programme 2004-2006	Semi-structured Interviews at home(n=10) and 1 in rehab centre	Qualitative Content analysis

O'Brien et al. 2008 [121] Qualitative Phenomenology Victoria, Australia	Perceptions of positive/negative aspects of community based progressive resistance strengthening training.	12 participants with PD. Age: 50-78 (mean 67.8 years). Gender: M=10 F=2 PD Grade I - IV Hoehn & Yahr, 2 – 92 months since diagnosis, living in community with PD, first experience of PRST.	9 semi-structured interviews at home and 3 carried out in quiet room in health centre	Grounded Theory and thematic analysis (QRS NVivo Version 7)
O'Brien et al. 2016 [122] Grounded Theory, Interpretive, constructionist Sydney, Australia	Experiences of exercise/ exercise behaviour following enrollment on supervised exercise program.	8 participants with PD. Age: 64- 85. Gender: M=6 F=2 Recruited via local PD support groups. Enrolled in 6-month exercise arm of falls prevention trial for which eligibility includes: diagnosis of idiopathic PD; able to walk independently with/without walking aid; stable anti Parkinsonian medication for > 2 weeks; >1 fall in past year or at risk of falls.	In depth semi-structured interviews at own home	Grounded Theory
Parsons and Stanley 2008 [123] Qualitative phenomenology Adelaide, South Australia	Experiences of occupational adaptation following ABI living at home in rural area (and social support services).	2 participants with mild to moderate ABI. Age: 30, 45. Gender: M=2 6 – 18 months post rehabilitation living at home, had received Brain Injury Rehab services, able to articulate experience, give informed consent.	Semi-structured interviews. Venue not stated.	Thematic analysis
Pretzer-Aboff et al. 2009 [124] Grounded Theory Maryland, United States	Barriers/ facilitators/ techniques which facilitate function and participation in activity and exercise.	3 participants with PD , formal caregivers (n=3); informal caregivers (n=4 spouse/significant other). Age: 75 – 82 (Mean 78.7). Gender: M=2 F=1 1 -17 years post PD diagnosis (mean = 7). 2 living in continuing care retirement community and 1 on own. Receiving social and/or healthcare.	Face to face interviews with 3 people with PD (2 separately and 1 with husband), 3 formal caregivers, 4 informal caregivers. Venue: quiet private place.	Thematic content analysis: coding and categorisation in to themes (NVivo)
Salamonsen et al. 2010 [128] Qualitative, interpretative Norway and Denmark	Experiences of unexpected courses of MS that relates to use of Complementary and Alternative Medicine.	12 participants with MS. Age: 39 – 55. Gender: M=3 F=9 6 – 21 years since diagnosis. Recruited from MS registry of patients with medical diagnosis; has experienced unexpected improvement or worsening of disease; and relate improvement /worsening to use of CAM.	Document analysis, qualitative one to one interviews. Venue not stated.	Document analysis, thematic analysis with case study used to represent findings
Sixsmith et al. 2014 [65] Qualitative, participatory North West England, UK	Experiences during National Service Framework implementation [7].	50 participants with LTNC: MS (n=17), Brain Injury (n=12) Parkinsons Disease (n=4), Stroke (n=9), Spina Bifida (n=7), Epilepsy (n=3), Cerebral Palsy (2), Cerebellar Syndrome (1), Lesch Nihan (1). Age: 20–79 Gender: M=29 F=21 Recruited at public workshop event, and day care centre. People with communication difficulties included.	Semi-structured interviews, followed by follow up interviews with 25 participants. Venue: day-care centres (31), residential centre (10), voluntary centres (8), warden housing (1).	Thematic analysis
Soeker et al. 2012 [82] Qualitative: interpretive Western Cape, South Africa	Perceptions and experiences of people with ABI regarding RTW rehabilitation.	10 participants with BI Age: > 18 Gender: M=9 F 1 Recruited from Occupational Therapy (n=5) and Road Accident Fund Organization (n=5). Mild to moderate BI (Glasgow Coma Scale) > one year, receiving RTW rehabilitation, previously employed.	In depth interviews in workplaces of 2 participants, homes of 6 of the participants, and at hospital for 2 participants.	Thematic content analysis

Turner et al. 2007 [131] Qualitative Phenomenology Queensland, Australia.	Experiences of people with ABI during transition from hospital to home	13 participants with ABI , and caregivers (11) Age: 19 – 53 (Mean 36.9). Gender: M=6 F=7 Recruited from hospital- based outpatient service and community-based case management service during 3 month transition from D/C to home representing variables 1. Type of ABI, TBI, 2. Severity of ABI/TBI (mild, moderate, severe), 3. Rural or metropolitan location 4. Amount of support available.	Semi-structured interviews at site of recruitment or own home (n=14) or by telephone (n=10).	Inductive Thematic Analysis
Turner et al. 2011a [132] Qualitative Phenomenology Brisbane, Australia	Perceived service and support needs of people with ABI and carers during transition period to home.	20 participants with ABI , and 18 family caregivers (n=11) Age: 17 -63 (Mean 40.2). Gender: M=15 F=5 Recruited from specialist inpatient rehabilitation unit.	In depth, semi-structured interview (prior to discharge, 1 month and 3 months post discharge) in home /hospital or telephone interview.	Thematic analysis (process open, axial, selective coding)
Turner et al. 2011b [133] Qualitative, Phenomonology. Brisbane, Australia	Perceptions of people with ABI during transition from hospital to home.	As above Same participants as above [132] but different phenomena explored.	As above	Thematic analysis
Twomey & Robinson 2010 [134] Qualitative Phenomenology Limerick, Ireland	Lived experience of fatigue management programme based on CBR principles /philosophy.	8 participants with MS Age: 29 -55 Gender: M=2 F=6 Recruited via MS Society and health professions for the MS fatigue management programme; people who had attended the fatigue management programme.	Individual interviews. Venue not stated.	Constant comparative analysis
van de Eijk et al. 2011 [75] Qualitative Phenomenology Nijmegen, Netherlands	Experiences of people with PD and informal carers of received healthcare.	39 participants with PD and 1 with Multi system atrophy. Carers (n=20) Age: 61.9 (mean) Gender: M=10 F = 30 Recruited via Neurology Departments and via Website of Dutch Parkinsons' Disease Association. Living independently, mean years since diagnosis = 5 years.	Five focus group discussions with people with PD (n=40) and 3 separate group discussions with informal carers (n=20)	Inductive analysis and coding
Van Rumbyke & Schneider 2013 [137] Qualitative Ontario, Canada	Experiences of people with MS of a targeted group exercise programme.	6 participants with MS Age: 58-72 Gender: F=2 Recruited from group exercise program for people with MS Women who were active in physical activity 2 days /week	Semi-structured individual interviews. Venue: not specified.	Thematic analysis
Whitehead 2010 [135] Qualitative Interpretive phenomenology Liverpool, UK	Experiences of people with PD of psychosocial impact of communication changes.	4 participants with idiopathic PD diagnosed > 5 years and their respective spouses (female: 3, male: 1). Age: Mean age 64. 29. Gender: M=3 F=1 Recruited via PD society using purposive sample; all receiving dopaminergic medication for the condition.	In depth one to one semi-structured interviews with people with PD with communication difficulties and carers (separate interviews) in own home.	Thematic analysis

* M = Male, F = Female, MS = Multiple Sclerosis, PD = Parkinsons' Disease, ABI = Acquired Brain Injury, BI = Brain Injury,

Table 2: Synthesised Findings (with associated categories)

Categories	SYNTHESISED FINDINGS
The rehabilitation programme/service promoted active participation, developed confidence and autonomy.	SF1: People with MS, PD and ABI experience interactions with some professionals/services which provide appropriate support, and promote active participation, choice, confidence and autonomy in decision making.
The supportive role of individual health professionals, staff/volunteers in the community was valued.	
The role of service user was as a passive recipient who was not involved in choices and decisions.	
Interactions with some health professionals felt de-personalised, medicalized.	SF2: People with MS, PD and ABI experience interactions with some health professionals which are disempowering and depersonalized, and do not accommodate individual preferences and needs.
Accessible information/education about condition, medication, interventions, strategies support and exercise not sufficient but recognized as useful.	
Communication skills of professionals varied and were recognized as important for a) giving individualized personal information including diagnosis and prognosis, b) listening to each individual's situation and c) developing a good relationship.	
People using services value professionals/leaders who have specialist, accurate knowledge about their long term neurological conditions (pathophysiology, symptoms, medication, equipment, intervention strategies).	SF3: People with MS, PD and ABI perceive that a combination of effective communication skills, specialist knowledge and an individualized approach to information provision is necessary to reduce uncertainty, increase awareness and improve control for people using (or leaving) the service. Experiences of receiving adequate, accessible, accurate information and education about the long term neurological condition and appropriate exercise/activity/support varied.
The potential of goals to provide structure, motivation and satisfaction within rehabilitation was recognized.	
Variations and lack of clarity regarding indicators of success and goals was experienced.	
Opportunities for social interaction with peers with similar long term neurological conditions was valued.	SF4: Indicators of success/outcomes/goals from community rehabilitation and support services vary and may not be clear to people with ABI and MS. The potential for 'goals' to provide structure, motivation and satisfaction is noted.
Sharing of experiences and support with group of other people with similar long term neurological conditions was important.	
Peer support resulted in feelings of encouragement, friendship, self-efficacy and successful self-management.	
Informal support from family and friends fulfilled physical, emotional and administrative roles for people living with a long term neurological condition in the community.	SF5: People with MS, PD and ABI value opportunities for peer support and social interaction with peers (people with similar long term neurological condition). These experiences may result in friendships, a feeling of collectivism, and encouragement for self-efficacy and self-management.
A perceived need existed for family support services to assist with challenges, provide support and help maximize the role of informal carers.	
Early period of transition to the community requires coordinated approach within and between services to prevent delay of support and rehabilitation provision.	
Support from case management services fulfilled multiple roles and was valued during the transition phase.	SF6: People with ABI and MS value informal support (physical, emotional, administrative) from family and friends, and perceive that the role of informal support could be maximized with appropriate assistance from community rehabilitation and support services.
Formal community rehabilitation and support services (therapy, vocational support, transport, care at home) were perceived to be limited by most people.	
	SF7: People with ABI and MS consider that a coordinated approach between community rehabilitation and support services is required to ensure continuity during transition to the community, and case management services may fulfil this role. Limited access to formal community rehabilitation and support services is experienced, by some people.

Table 3: Meta aggregation example for Synthesised Finding 1 (12 findings which formed 2 categories)

Findings U = unequivocal C= Credible	Categories	Synthesised Finding (SF)
<i>Participants described ownership, active participation and empowerment as a central feature of their experience of the programme</i> MS [134] U <i>Developing responsibility, encouragement to make changes and take control</i> MS [128] U <i>Important to be Involved in decisions and 'in control'</i> PD [75] U <i>Important to understand the aims and purpose of the group rehabilitation programme</i> ABI [117] U <i>Insistence of 'being involved' over period of time increased credibility as 'team member' in relation to own rehabilitation plan.</i> ABI [113] U <i>Feeling relaxed, positive and self-confident</i> MS [103] U <i>Enjoyment</i> MS [101] U	<div> The rehabilitation programme/service promoted active participation, developed confidence and autonomy. </div>	<div> SF1. People with MS, PD and ABI experience interactions with some professionals/services which provide appropriate support, promote active participation, choice, confidence and autonomy in decision making. </div>
<i>Members of the healthcare team (nurse practitioner, neurologists, physical and occupational therapists) were facilitators to optimise function</i> PD [124] C <i>Staff and volunteer support was valued</i> MS [103] C <i>Impressed with Occupational Therapy support</i> ABI [123] C <i>Impressed with professional health services</i> ABI [123] C <i>Practical support from occupational therapist and emotional support from psychologist valued</i> BI [77] U	<div> The supportive role of individual health professionals, staff/volunteers in the community was valued. </div>	

Table 4: Meta-aggregation example for Synthesised Finding 2 (9 findings which formed 2 categories).

Findings U = Unequivocal C= Credible	Categories	Synthesised finding (SF)
<i>Losing bodily competence “feeling like diagnosis... feeling like ‘a patient who could not do anything for herself’”. MS [128] U</i> <i>Treated as “just another brain injury” TBI [113] U</i> <i>Engulfed by a medical system and professional control TBI ([113] U</i> <i>Passive Role and lack of involvement in decisions ABI [113] U</i> <i>Perceptions that power imbalances exist between service users and service providers ABI [65] U</i>	The role of service user was as a passive recipient who was not involved in choices and decisions.	SF2. People with MS, PD and ABI experience interactions with some health professionals which feel, disempowering and depersonalized and do not accommodate individual preferences and needs.
<i>Process of deciding and obtaining power mobility challenging: lack of respect for the persons with MS and their family members from key figures involved. MS [97] C</i> <i>Insensitivity when giving feedback about driving performance MS [956] U</i> <i>Lack of psychosocial support; Positive experiences of getting help were in the minority MS [116] U</i> <i>Insensitivity of health professions connected with ‘invisible symptoms’ e.g. pain, fatigue. ABI [98] U</i>	Interactions with some health professionals felt de-personalised, insensitive, medicalized.	

Table 5: Meta-aggregation process for Synthesised Finding' 5 (23 findings which formed 3 categories).

Findings U = unequivocal C= Credible	Categories	'Synthesised finding' (SF)
<i>Support and opportunities for social interaction with other people with PD. PD [135] U</i> <i>'Fun factor' associated with socialization and participation MS [103] U</i> <i>Social value of the programme MS [101] U</i> <i>Social aspects of group membership valued MS [99] U</i> <i>Enjoyed social interaction that occurred as part of the exercise group MS [99] U</i> <i>Outcomes predominantly on social aspects of the programme rather than on the physical ones PD [121] U</i>	Opportunities for social interaction with peers with similar long term neurological conditions was valued.	SF5. People with MS, PD and ABI value opportunities for peer support and social interaction with peers (people with similar long term neurological condition). These experiences may result in friendships, a feeling of collectivism, and encouragement for self-efficacy and self-management.
<i>Peer support, commonalities and friendship gained MS [104] U</i> <i>Initial worries and concerns about group setting but over time found it supportive MS [104] U</i> <i>Group choral singing influenced physical and mental health PD [106] U</i> <i>Shared experience, support and shared voice MS [134] U</i> <i>Disease-specific exercise programme beneficial for sharing information with others in 'the same boat' PD [121] U</i> <i>Support and reassurance gained from others in the same situation. BI [83] U</i>	Sharing of experiences and support with groups of other people with similar long term neurological conditions was important.	
<i>Support from the group was important PD [105] U</i> <i>Peer support groups with people with MS/ expert patients contributed to self-efficacy/ successful self-management. MS [116] U</i> <i>Information and advice from peers with MS [97] C</i> <i>Peer support provided reassurance BI [83] U</i> <i>Sharing of knowledge and experiences which could potentially assist others MS [137] C</i> <i>Group sessions provided enjoyment, reassurance and shared experiences MS and ABI [100] U</i> <i>Motivation and support from group structure of the class MS [99] U</i> <i>Positive effects of exercising in a group include shared understanding, incentive, competition, and motivation PD [122] U</i> <i>Empowerment, confidence and sense of achievement gained from group experience MS [99] U</i> <i>Learning from group rehabilitation helped adapt to change in home role/responsibility ABI [117] C</i> <i>Encouragement from peers with MS on programme. MS [101] U</i>	Peer support resulted in feelings of encouragement, friendship, self-efficacy and successful self-management.	

Box 1: JBI critical appraisal questions [70].

1. Is there congruity between the stated philosophical perspective and the research methodology?
2. Is there congruity between the research methodology and the research question or objectives?
3. Is there congruity between the research methodology and the methods used to collect the data?
4. Is there congruity between the research methodology and the representation and analysis of the data?
5. Is there congruity between the research methodology and interpretation of the results?
6. Is there a statement locating the researcher culturally or theoretically?
7. Is the influence of the researcher on the research and vice versa addressed?
8. Are participants and their voices adequately represented?
9. Is the research ethical according to current criteria, or for recent studies, and is there evidence of ethical approval by an appropriate body?
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

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Box 2: Characteristics of community rehabilitation and/or support services.

Rehabilitation and support in the home and local environment

- Rehabilitation and support at home: general (PD, MS, ABI); vocational rehabilitation (ABI, MS); support for communication (PD); goal directed therapy (TBI)
- Care, support and rehabilitation within residential care centre (PD)
- Following discharge from hospital (ABI)

Day Centre and Outpatient services

- Group Programmes e.g. exercise (PD, MS); support (PD, MS); therapeutic interventions (MS; mindfulness based Cognitive Therapy (PD); fatigue management (MS); return to work programme (ABI); choral singing therapy (PD).
- Complementary and Alternative Medicine (MS)
- Power mobility and driving (MS)
- Memory rehabilitation (ABI)
- Condition specific outpatient clinics (ABI)

Activity and participation domains of the ICF [88]: d3 Communication; d4 Mobility; d 570 looking after one's self (self-care); d 6 domestic life and d7 interpersonal interactions and relationships.

Geographical location: Australia [14,90,95,98,101,102,121-123,131-133]; New Zealand [106]; Canada [107, 111,113,114,137]; USA [97,124]; UK [65,80,83,96,100,103-105,108,116,135]; Netherlands [75]; Scandinavia [117,128]; Republic of Ireland [99,134]; South Africa [82].

Figure 1: PRISMA 2009 Flow Diagram [93]: Patient reported experiences of using Community Rehabilitation and Support Services whilst living with a Neurological Condition: A Systematic Review.